

ENHANCING EDUCATION AND PRACTICE

Infection Control in the Context of Hepatitis C Disclosure: Implications for Education of Healthcare Professionals

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ABSTRACT **Introduction:** *Previous investigation has shown that the health sector is a main source of discrimination against people with hepatitis C. This paper examines the perceptions and experiences of people with hepatitis C of their interactions with healthcare workers, particularly examining the implementation of infection control precautions. We contend that rather than applying infection control precautions universally, health care workers make judgements about individual patients and the likelihood that they are infected with hepatitis C. Thus, infection control practices can be used as a tool to discriminate against people with hepatitis C. Social identity theory is used to illustrate these insights and to propose recommendations for education of health care workers.*

Method: *Semi-structured interviews with 19 people who had hepatitis C were conducted. The analysis examines issues of diagnosis, discrimination and disclosure in relation to healthcare workers' use of infection control procedures during clinical interactions.*

Results: *Participants described non-compliance with infection control guidelines by healthcare workers in a range of settings. In some instances, participants expressed disapproval of non-compliance, at other times participants felt vulnerable and discriminated against. Participants felt obliged to disclose their infections, but some decided against future disclosure because of negative reactions from healthcare workers. Infection control procedures were used as a tool to discriminate against some participants.*

Discussion: *Non-compliance with infection control guidelines persists among healthcare workers and can be identified by patients. A minority of workers use infection control as a discriminatory tool against those with hepatitis C. Further intervention is required to ensure infection control guidelines are enacted in the manner intended.*

KEYWORDS *Hepatitis C, infection control, discrimination, education.*

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Introduction

In Australia, the hepatitis C epidemic is currently having a major impact on the provision of healthcare (National Centre in HIV Epidemiology and Clinical Research, 2002). The healthcare setting is a significant source of hepatitis C-related discrimination (Crofts *et al.*, 1997; Anti-Discrimination Board of New South Wales, 2001; National Centre in HIV Social Research, 2001; Dunne & Quayle, 2002; Treloar *et al.*, 2002). Inadequate knowledge of the virus and the confounding of hepatitis C infection with injecting drug use (IDU) often underpins hepatitis C-related discrimination (Anti-Discrimination Board of New South Wales, 2001).

Social identity theory (Tajfel, 1981) is useful in examining the foundation and expression of stereotypes that manifest as hepatitis C-related discrimination. Categorising people as members of in-groups and out-groups is based on stereotypical perceptions of difference. One's self-esteem is enhanced through reinforcing the status of their group by differentiating it from relevant out-groups (Hamner, 1992). Some social groups and socially proscribed practices, such as IDU, may be seen as a threat to the community's well-being (National Centre in HIV Social Research, 2001). Social identity theory predicts that some individuals and groups will distance themselves from people who inject in order to maintain in-group safety and defend in-group values. For example, healthcare workers may create and police boundaries to delineate their hegemonic in-group (of rational, healthy, law-abiding citizens) (Gilmore & Somerville, 1994) from those deviant "others" who compromise their health by injecting drugs.

Discrimination often occurs when practitioners make judgments regarding their patients' risks for hepatitis C infection which is contrary to one of the most fundamental notions underpinning modern health systems, that is, infection control precautions (Centers for Disease Control, 1988). Judgements about the use of infection control precautions should be made according to the degree of risk of exposure inherent in the procedure and not knowledge or judgements of the patient's infectious state. Many studies have documented a lack of compliance with infection control guidelines (Treloar *et al.*, 1996; Henderson, 2001).

In this paper we examine descriptions of infection control experiences in healthcare settings reported by people with hepatitis C. In addition, we consider the literature concerning social identity theory and the prevention of stereotypes and make recommendations for future education programs for healthcare workers.

Method

Participants were people living with hepatitis C in Sydney, Australia. Participants were recruited via an advertisement inserted in *The Hep C Review*

(published quarterly by the Hepatitis C Council of New South Wales), and by snowballing through the social networks of participants.

In a 45–60 minutes semi-structured interview, participants were asked to discuss their life history and a range of health and social issues pertaining to living with hepatitis C infection, including diagnosis, disclosure and hepatitis C-related discrimination. This project had approval from the University of New South Wales Human Research Ethics Committee. An interviewer experienced in research with marginalised people (MH) conducted all interviews.

The semi-structured nature of the interview scheduled allowed participants to elaborate on the interview topics. In discussing hepatitis C-related discrimination and health care, participants related experiences and concerns about their health care in relation to infection control. Analysis of data for this paper focused on the sections of text relating specifically to infection control. Analysis of other issues relating to the experience of living with hepatitis C are presented in the project report (Hopwood & Treloar, 2003). The authors independently coded the transcripts using a code list constructed from issues emerging from the transcripts. Researchers compared coding decisions and discussed any differences until consensus was reached. The coded interview transcripts were entered into qualitative software, NVIVO (QSR, 1999). The authors reviewed data relevant to the issue of infection control to identify and describe themes within the interviews that emerge as significant or important to individuals. Pseudonyms were assigned to each participant and quotes selected to illustrate the three main themes: doing the right thing; infection control as a discriminatory tool; and impacts on future disclosure.

Results

Nineteen participants were aged between 22 and 72 years with a mean of 45 years. Twelve participants were women. Eight cited IDU as their source of infection, six reported medically acquired infections and five participants reported multiple risk factors. Most had been diagnosed between 1989 and 2001. Two participants had been diagnosed with non-A non-B hepatitis during the 1970s (prior to the identification of hepatitis C).

Doing the “right thing”

There was a strong pattern of belief that disclosing their hepatitis C infection was the “right thing” to do. In these cases, disclosure was related to participants’ concerns for the protection of healthcare workers and other patients. Participants saw themselves as partners within a therapeutic relationship and extended notions of care and trust to their healthcare workers.

“I’m obliged to tell them...You don’t expect someone to treat you where there are dangers involved without disclosing those sorts of things.” (Susie)

In some instances, disclosure was met with unequivocal applications of infection control principles. However, these situations were described as atypical.

“I say ‘Excuse me, did you know that I have hepatitis C?’ and a few of them [healthcare workers] say ‘We treat everyone the same’. There’s not many people who do that.” (Claris)

Participants were disapproving of noncompliance with infection control guidelines and described workers as “stupid to themselves”, “compromising the level of care” and motivated by a lack of care for patients.

“Most nurses don’t bother taking the universal precautions they are supposed to take with every patient. In fact, they only take precautions ... to protect themselves, and they don’t actually think about protecting you against other patients in the ward. A nurse will come in with gloves on but they’ll go to someone over there with those gloves on, then they’ll come over to you with the same pair of gloves on. So it’s obvious that they’re not worried about transmitting something from him to me.” (Sebastian)

A scenario of organisational noncompliance with infection control guidelines was mentioned by a number of participants, being placed at the end of the day’s surgery list. For example, Mavis described the sensitive handling of her hepatitis C disclosure at the interpersonal level, yet recognised that organisational level practice compromised infection control.

“I told the doctor how fearful I was of being shunned because I’ve got [hepatitis C] ... He was most discreet about it and had a little word with the nurses. They just quietly said ‘We understand’ and that’s all they said ... but I had to go to theatre last because they don’t want you in a bed before anyone else, which apparently is wrong because they’re supposed to make it completely sterile for every new patient.”

Infection control as a discriminatory tool

Participants’ responses to noncompliance generated a range of reactions related to their perceived degree of vulnerability within a situation. In some situations where participants admonished healthcare workers, they acknowledged the discriminatory judgements on which noncompliance was based but did not necessarily feel personally discriminated against. In other instances, the

selective use of infection control practices was reported to be extremely distressing.

“ [The dentist] only had to do some routine stuff and first of all they came in geared up like they were about to land on Mars and the guy was really nervous. He was terrified. Then while I was standing there waiting to pay, he had everyone from the whole surgery in there, scrubbing down the walls, cupboards, everything—all gowned up the lot of them. Everyone in the waiting room could see this. The greatest over-reaction. I mean anyone could have been in that surgery carrying a virus that they needed to be protected against. It was so directed at me. They didn’t wait until I left the premises, they didn’t wait for anything, they just did a big show...Don’t come back, I think that was the message.” (Deb)

Typically, participants did not challenge the behaviour of healthcare workers, even in situations when participants felt in control. Hilda described approaching three surgeons to perform elective surgery. She found the approach of the third surgeon to be acceptable and conforming to her view of how universal precautions should be applied.

“I went to see him and he didn’t talk about [hepatitis C]. He knew I had it, of course, but he didn’t even talk about it. Because it’s not my responsibility—it’s my responsibility to look after my own and so on—but, if I were a surgeon, then it would be my responsibility. It would be ‘alright [I will assume everyone] has hep C so I have to clean those special ways. I have to wear double gloves’. So that’s when I thought ‘I don’t go to those [other surgeons]’ because, if they look at it that way, I don’t need that.”

The difficulty in challenging perceived discriminatory use of infection control practices was even greater in situations where the participant felt vulnerable. For example, Sebastian described instances of noncompliance in hospital wards rather than in the specialist haemophilia centre in which he usually receives care.

“I’ve been admitted into hospital a couple of times and [hepatitis C] is an issue with them on the wards...because you don’t want to rock the boat too much you can’t really say too much if you think you’re being discriminated against, because there are extra things that have to be done because of the haemophilia...I take morphine on a four-hourly basis and if you upset the nurses they might not...I’ve seen it happen, they just delay medication like that because they’re annoyed. So you can’t afford to upset them because they’ll get you back somehow.”

Impacts on future disclosure

Although disclosure of hepatitis C infection was typically described by participants as part of their approach to healthcare, some have decided not to disclose in future because of previous negative reactions. Deb had “always believed” in disclosure but following her experience described above, she was sufficiently distressed to decide “never [to] tell another medical professional as long as I live”.

This demonstrates a teleological negative relationship between disclosure, discriminatory use of infection control practices and subsequent decisions against future disclosure. Typically participants felt that healthcare workers assumed that affected patients would disclose their infection and that patients who did not disclose were assumed to be without infection.

Discussion

Decisions to use infection control should be independent of the person being treated and dependent on the level of risk inherent in the procedure. Infection control procedures imply that the notion of in-group and out-group differentiation is irrelevant. However, our data provides evidence that some healthcare workers make decisions about infection control procedures according to judgements about patients' infectious risk.

The findings demonstrate instances where participants see noncompliance with infection control guidelines by healthcare workers in terms of inappropriate professional practice. There were instances in which participants felt relegated to an out-group by healthcare workers and felt socially ostracised. These instances may occur when participants feel vulnerable within the situation.

From the perspective of the social identity framework, infection control was perceived as a tool to express disapproval about participants' lifestyle choices and social group membership. Healthcare workers differentiate between acceptable patients and those considered dangerous to the health of others, thereby requiring “special” procedures. This type of reaction can result in patients deciding to withhold disclosure of infection. Healthcare workers, who rely on patients' disclosure of infection to implement infection control precautions and who also discriminate against those who do disclose, perpetuate the risk to themselves and other patients. There will be always be people with hepatitis C who are unaware of their infection, so noncompliance with infection control guidelines may have significant implications for spread of the epidemic.

People with hepatitis C are more likely to disclose their infection within healthcare settings than in community or social contexts which may partly account for the common occurrence of hepatitis C-related discrimination in health settings. These findings were drawn from reports of participants'

experiences and perceptions: previous experiences of discrimination may sensitise individuals to interpretations confirming their experience. However, our data did include reports of appropriate and compliant infection control practices. Noncompliance with infection control has long been a target of research and intervention. These data suggest that there may be persistent attitudinal bases to poor infection control practice.

Our data did not demonstrate differences in experience between people with hepatitis C acquired through medical procedures and those who acquired it through IDU. As others have argued, attitudes to hepatitis C are intimately tied to attitudes to injecting drug use (Anti-Discrimination Board of New South Wales, 2001). From these data, the disclosure of hepatitis C infection was sufficient for healthcare workers to assign these individuals to an out-group.

Our findings cannot claim to represent all infection control related episodes experienced by people with hepatitis C. However, they do provide insight into a range of experiences with direct implications for education and professional training of healthcare workers. By using theories of social identity and attitudinal intervention to critically examine these data, we can contribute to discussion around how attitudes to people with hepatitis C can be addressed within education systems.

Research on changing attitudes of health professionals has focused on interventions to increase knowledge about the target (out)group (Schaller *et al.*, 1996), exposure to the target group (Birmingham & Kippax, 1998; Roth *et al.*, 2000; Hayes *et al.*, 2002; Wilkinson *et al.*, 2002) or protest which seeks to suppress stigmatising attitudes (Corrigan *et al.*, 2001). However, stereotypical attitudes are resistant to change. Although knowledge may increase after intervention, attitudes may be unchanged (Hayes *et al.*, 2002). Exposure to the target group has had some success (Sheridan *et al.*, 1994) but protest has shown to be ineffectual in changing attributions about the target group (Corrigan *et al.*, 2001).

Contact with an out-group may challenge previous unconditional learning and judgements about that group (Langer & Moldoveanu, 2000) and also reduce social distance between in-group and out-group (Pittman & Gallois, 2000). Contact with an out-group, allows the opportunity to see the individuals as occupying many stations in life and having a variety of histories.

These findings may provide some direction for future programs to address healthcare workers attitudes to stigmatised groups. Rather than focusing on the method of delivering education, these programs should be based on the recognition that a moral judgement, such as a stereotype, is dependent on an understanding of the origin of difference rather than on evaluation of the characteristics of difference (McCauley *et al.*, 1995). This points to a need to provide counter-arguments in teaching about infection control procedures. To focus not just on technical competence, but to examine the beliefs and attitudes of healthcare workers regarding marginalized groups and demonstrate how these may impact on decision making. Intervention strategies, such as role

modeling and contact with out-groups, may be augmented by considering judgements made about the origins of difference between people. Social identity theory is helpful in uncovering and challenging stereotype formation and could be widely utilised in educational curricula for healthcare workers.

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